

# 2002

# The Research Connection

The Psychosocial & Nursing Advisory Board to  
the New Jersey Commission on Cancer Research

Editor: Kathleen Neville, Ph.D., RN

Summer 2002

The Joint Psychosocial & Nursing Advisory Group to the NJCCR was appointed to advise the Commission of special research needs pertaining to nursing, psychology, sociology, and related disciplines for the purpose of addressing gaps in vital areas of cancer research and cancer care in New Jersey.

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## DEMYSTIFYING PSYCHOSOCIAL RESEARCH: THE JOURNEY FROM CLINICIAN TO EDUCATED RESEARCH CONSUMER AND ON TO INVESTIGATOR

by  
Denise Adler, MA  
Program Chair

*Every time you ask yourself WHY,  
you are engaging in research!*

Coping with daily news reports of “incredible breakthroughs” and “astounding reversals of previously accepted wisdom” highlights both the importance of, and the confusion surrounding that mysterious word: *research*. In an attempt to demystify the concept and reinforce the critical role that research plays in healthcare, the Psychosocial Advisory Group of the NJCCR presented a daylong seminar on June 5, 2002 at the American Cancer

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Society, New Brunswick, N.J. This seminar, *DEMYSTIFYING PSYCHOSOCIAL RESEARCH* focused on exploring the need to properly understand and evaluate research findings. In addition, the seminar was planned to encourage clinicians to consider participation in the research process and to appreciate the significant contribution that can be made to the knowledge that drives healthcare. The outstanding faculty provided insights into the core values of scientific evaluation, the role of clinical trials, evaluating the literature, use of the web as a resource, current New Jersey research, finding and obtaining funding, and finally, translating the original thought into a definable research project. (See box, "Faculty List")

***"Who ME? Do research?"***

***I can hardly do what has to be done in the day, and besides, research is only for experts!"***

In the current environment with limited budgets, severely reduced staff levels, and more pressing daily concerns, many clinicians cannot imagine themselves as researchers. The truth is that everyone who provides care, thinks about it, or plans and administers healthcare is conducting a form of research every day. Each time you wonder why A often follows B, or consider that some outcomes are better, worse, or different, the research process has begun. While the thought of formalizing your idea into a scientifically acceptable, clearly delineated, and achievable research question may be intimidating, the speakers at the seminar proposed that it is essential that clinicians become intimately involved in the research process. It is the clinician who can identify the essential questions that appear daily, and "connect the dots" in a more knowledgeable way. Participating in research also provides a way of "stepping back" and appreciating the larger picture of what is being accomplished. Moreover, being intelligent consumers of research literature and clinical trial materials is critical in clinical decision-making, patient assistance and appropriate referral.

Research was defined as: "A systematic inquiry that uses orderly disciplined methods to answer questions or solve problems" (Neville, 2002, June). The purposes of research may include:

- Identifying
- Describing
- Exploring
- Predicting and Control
- Explaining

Most currently accepted practices are the result of painstaking and careful research. The role of clinical experience, literature and theory in forming a question is essential, as is the importance of following clear guidelines for ethical research, including the role of the Institutional Review Board and Informed Consent.

Instincts and passion should direct the researcher. Psychosocial research has provided insights in: coping/loss/grieving, hope/hopelessness, social support, communication, pain management and responses to illness. Some of the pressing issues for future psychosocial research include: quality of life, pain and symptom management, communication, palliative care and decision-making and informational needs of patients and families.

***"How do I know if this is a clinical trial I should present or advise my patients to consider? The information can be so confusing!"***

Clinical Research was defined as an essential tool identifying effective new treatments, comparing them to the standard regimen, to further understand how they affect new populations, and exploring the relationship of medical care and psychosocial issues (Kowalski, 2002, June).

Clinical trials, which might be conducted by the government, independent organizations, physicians, social workers, nurses, in academic, community and rural settings, should be carefully evaluated before participation by patients is supported. A number of questions should be asked and include:

- Who is conducting the research, what is their experience and has it met IRB approval?
- Is the purpose worthwhile? What is known and what to be learned?

- What are the procedures; consider the danger, costs, time and effort involved?
- What are the risks; how often, how serious, level of acceptability?
- How big and how long is the study, and are there alternatives?

Each phase of clinical research raises concerns that must be addressed about the safety, efficacy and benefits of the new treatment and/or drug. Acknowledging that most questions cannot be answered by a single research study, participants were encouraged to participate in well-designed and accepted trials when possible.

***“Where do I start?”***

***How do I find the information I need and how do I identify quality and excellence?”***

Finding and evaluating literature about a research question is the critical first step, but can also be a daunting challenge. A great deal is published, but as has become apparent in recent years, studies can be flawed, both from inexperience, misplaced eagerness or outright fraud. In addition, studies that cannot be replicated become suspect. (Budin, 2002, June; Patrick-Miller, 2002, June). The need to find and examine good resources for formulating a new question, evaluating the findings of a new study, and making recommendations for patient care are especially important.

Healthy skepticism is necessary in evaluating whether research results are based on systematic observation, are testable and are publicly verifiable. Types of studies include: descriptive, co relational, experimental and quasi-experimental. Evaluating an article generates a number of important questions:

- Could I re-create this study with this information?
- Does the design match the research questions?
- What methods were used, and are they consistent?
- Where was the study done and does that site match the design described?
- How were participants recruited?

- How was the analysis conducted and is it consistent with approved procedures?
- What were the limitations, assumptions, and initial methodological concerns?
- Are the results significant, do they make sense, and do they have implications for clinical care?

While journals abound, and seem to be proliferating on a daily basis, the Internet has provided a significant new tool for research and investigation. While journals may be known, and clearly peer-reviewed, some of the new Internet sites might be less familiar. Care must be taken to identify the sources and knowledge base of the Internet site. A number of appropriate sources and the means of following them were provided to participants.

***“This all sounds very complex; how can we in New Jersey compete, and anyway, where would I find the resources to even consider trying this myself?”***

Opportunities are improving for funding and grants in New Jersey, as well as increased collaboration and interaction among academic and clinical researchers. (Hill, 2002, June).

Seeking funding for research projects may appear overwhelming, but as with most new tasks, can be approached in a systematic way. (Adler, 2002, June; Hallissey, 2002, June). The most important issue is to be realistic in the assessment of what can be achieved in a particular setting, with the time, staff and institutional resources available. Setting a realistic, achievable budget is the first step, and assuring a funding source that the goals and methods are achievable will assist in convincing reviewers that they should provide support. The importance of a careful, systematic approach to grant writing was emphasized. Following guidelines is essential, and a proposal must include the basic issues to assure the funders that:

- The problem is important the and study is justified and innovative
- The objectives are clear and concise

- The methods fit the problem and are achievable
- Evaluation is built into the process
- Literature supports that the problem has not already been investigated
- The qualifications of the project director and institution merit confidence
- The results will be disseminated and can be replicated
- The budget is reasonable and consistent

An applicant's track record is one of the most important considerations in awarding large grants. Consequently, the participants were encouraged to join larger studies first, or to seek modest pilot funding as an initial step. Large National Institutes of Health or Centers for Disease Control and Prevention grants are generally collaborative, or developed following intensive pilot studies.

Funding can be obtained from hospitals or universities, local civic groups, community organizations, regional or national healthcare agencies, professional organizations, corporations and industry, individual donors, state health agencies and other sources. These should be explored as an initial step, as their requirements may be less intimidating and they often are eager to fund projects in the community. Understanding and following their guidelines is the most critical step. Information about the availability of grants, former recipients, annual reports and new guidelines are available on the Internet, or from the Foundation Center in New York. Call the funding source with questions.

Funding is extremely competitive, especially in the current financial environment, in which many budgets are being cut and resources are limited. One must always consider the benefits of the funding vs. the time and effort to obtain them. However, researchers should not be discouraged; funding is still available for good, well-considered and important problems, and while the hunt may take some time, the rewards for the outcome are considerable.

Using clinical experience, narrowing the issues to one, "answerable" question, seeking academic partnerships and moving forward can provide an opportunity to make a significant contribution. (Axelrod, 2002, June).

***"Could I REALLY do this?"***

Each clinician can examine the opportunity to plan, participate or refer patients to clinical research. In addition, understanding what you are seeing, reading and hearing is essential for healthcare professionals. Experienced researchers are all around, and ready to mentor the novices. Try it!

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*As you can appreciate from the previous article, this conference provided a basis to understand the importance research has in the fight against cancer. Below, Dr. Budin provides a summary of her workshop discussion.*

## **Beyond Books and Journals: Electronic and Web Based Resources to Facilitate Research**

by

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The amount of scientific literature available today can be overwhelming. It is estimated that the amount of scientific literature doubles approximately every 5 years. There are more than 6,000 new journal articles published each day. The number of nursing research journals has increased by more than 575% since 1961. Therefore, the ability to effectively use computerized databases to search literature is essential to being a reasonably informed researcher.

The use of computers and the explosion of information technology has become an integral part of research. Computers are an invaluable tool for researchers and consumers of research because of their speed, accuracy, and flexibility. A major task for all health care professionals is to process and integrate information so that it becomes useful knowledge --- knowledge that can guide clinical practice. We must be aware of and have easy access to the information available. Computer applications that support the research process are numerous.

This article will provide an overview of the literature review process and will also discuss a variety of computerized search strategies including electronic databases and selected web sites of interest to those involved in psychosocial

oncology research. Guidelines on evaluating web sites will also be included.

After a researcher decides on the problem to study, there is a need to find out what has already been researched in the area, to get all the ideas necessary to help develop the theoretical framework and hypothesis, and to decide on the research methods to use. A careful, systematic, and well-organized literature review will include recent publications and will go back as far as is consistent with the nature of the problem chosen for study.

A literature review is a summary of current empirical and theoretical knowledge about a particular practice problem that provides a basis for the study conducted. A literature review summarizes what is known and not known about a topic. It identifies gaps in the research and also provides a guide for all steps in the research process

Scientific literature includes empirical literature, i.e. reports of findings from relevant studies as well as theoretical literature -- concept analyses, theories, and models that support the research purpose. Sources of research reports can include original research articles, replication studies, integrative reviews or published summaries of research, meta-analysis, and articles that discuss theories & models.

The first step in conducting a literature search involves identifying and locating sources. Researchers typically search academic and special libraries. Interlibrary loan departments are also useful if sources are difficult to locate. A computerized search of databases, as well as Internet search and retrieval of electronic sources are invaluable in identifying relevant sources of information.

Electronic databases contain listings of the references (*and possibly abstracts*) from selected research journals, accumulated over the years. Electronic databases are stored on CD-ROM or on the Internet. The most popular electronic databases, relating to health care, are likely to be available in health science and university libraries.

One of the most popular electronic databases is MEDLINE. Abstracts and reference location materials for articles from a variety of medical and health science research journals can be found here, and it is all offered free. Unfortunately, there are a huge number of medical and allied journals in this database, so you have to target your search very carefully, or you will end up with thousands of articles.

#### PubMed

[<http://www.ncbi.nlm.nih.gov/entrez/query.fcgi>] is a special search interface for MEDLINE from the National Library of Medicine. A useful tutorial for PubMed can be found at [[http://www.nlm.nih.gov/bsd/pubmed\\_tutorial/m1001.html](http://www.nlm.nih.gov/bsd/pubmed_tutorial/m1001.html)]

If your topic is more psychological than physiological in nature, PsychINFO [<http://www.apa.org/psycinfo/>] may be useful. For example, an abundance of stress and coping research is indexed here.

CINHAL, the Cumulative Index to Nursing and Allied Health Literature contains the most articles from nursing journals. This database provides authoritative coverage for the professional literature in nursing and 17-allied health disciplines, biomedicine, consumer health, and health sciences librarianship. Virtually all nursing journals are indexed, along with publications from the American Nurses Association and the National League for Nursing. CINAHL also provides access to health care books, book chapters, pamphlets, nursing dissertations, selected conference proceedings, audiovisual material, and educational software.

EBSCO is a multi-discipline, full-text database of more than 2,300 scholarly journals. The diverse, scholarly content within this database covers social sciences, humanities, education, medical sciences, etc.

Some additional resources that are particular interest for cancer researcher include:

#### CANCERLIT®

- [http://www.cancer.gov/search/cancer\\_literature/](http://www.cancer.gov/search/cancer_literature/) - this is a bibliographic database that contains more than 1.5 million citations and abstracts from over 4,000 different sources including biomedical journals, proceedings, books, reports, and doctoral theses. The database contains references to cancer literature published from the 1960s to the present and is updated with more than 8,000 records every month.

PDQ or the Physician Data Query - [http://www.cancer.gov/search/clinical\\_trials/](http://www.cancer.gov/search/clinical_trials/) - is a comprehensive database produced by the National Cancer Institute, provides up-to-date cancer information for patients and their families, health professionals, and other people interested in educating themselves about cancer. Information from PDQ is available on the Internet through - <http://cancer.gov>, the NCI Web site, which features interactive tools for online searching.

OncoLink - <http://oncolink.upenn.edu/> is directed toward physicians, health professionals, social workers, and cancer patients and their supporters. This was the first multimedia cancer information resource on the Internet. OncoLink offers state of the art, well organized and consistent quality information. The University of Pennsylvania developed this Web site in 1994.

The Surveillance, Epidemiology, and End Results (SEER) Program of the [National Cancer Institute](http://www.nationalcancer.org) is the most authoritative source of information on cancer incidence and survival in the United States. It can be accessed at : <http://seer.cancer.gov/>

SEER data are used by thousands of researchers, clinicians, public health officials, legislators, policymakers, community groups, and the public. SEER provides cancer incidence, mortality, and survival data in an annual cancer statistics review, in monographs on relevant topics, through the Web site, and in a public use data file. SEER distributes software tools for the analysis of SEER and other cancer databases. SEER data and resources are made available on this site, free of charge.

The American Cancer Society - <http://www.cancer.org> provides information about cancer as well as information about the American Cancer Society, its publications, programs, and local offices. One may use this resource to locate the nearest regional unit and learn about local services. The Society also produces many fact sheets about cancer.

With the proliferation of numerous Web sites, it is important for consumers to evaluate the quality of these sites. A good Web site is a resource users turn to first in their search for timely, comprehensive, and accurate information to satisfy their needs. A quality Web sites must be well designed, helping both naïve and experienced users to rapidly locate the information they are seeking, even when they are not sure exactly what they are looking for. The most important feature of a good web site is its content. The content reflects the purpose of the Web site. A user should be able to quickly assess the goals of the Web site and its intended audience. There should be a constant stream of quality information feeding into the Web site. This content often comes from a variety of sources and must be shaped into a standardized “look and feel” in keeping with the graphical and information design of the Web site. This information must be validated and tracked to insure its origin and accuracy. Government or University run sites, without marketing, social or political agendas, are usually good sources for scientific and medical information. An editorial board should be available to review material, and respond to questions or requests for additional information. A good site should also link to other sources of medical information and should be updated on a regular basis. Information graphics and multimedia files should be available to enhance the information. Lastly, the site should offer information either without charge, or with good value for the fee.

## SAVE THE DATE

### *Cancer and Aging: A Call to Action*

**Princeton Marriott Forrestal Village,  
Princeton, NJ  
October 4-5, 2002**

*Distinguished Speakers:*

**Joseph Bailes, MD**, Past President, American Society of Clinical Oncology

**Lodovico Balducci, MD**, Professor & Head, Geriatric Oncology, H. Lee Moffitt Cancer Center

**Ann Berger, MD**, Chief, Pain & Palliative Care Service at National Institutes of Health

**Deborah Boyle, RN, PhD**, Advanced Practice Nurse Liaison, MD Anderson Cancer Center

**Martine Extermann, MD, PhD**, Assistant Professor, H. Lee Moffitt Cancer Center

**William Ershler, MD**, President, Institute for Advanced Studies on Aging & Geriatric Medicine

**Jimmie Holland, MD**, Professor of Psychiatry, Memorial Sloan-Kettering Cancer Center

**Laura Hutchins, MD**, Director, Division of Hematology/Oncology, University of Arkansas

**Richard Payne, MD**, Chief, Pain and Palliative Care Service, Memorial Sloan-Kettering Cancer Center

**Kathy Smolinski, LCSW**, The Sidney Kimmel Comprehensive Cancer Center at Johns Hopkins

**Rosemary Yancik, PhD**, Chief-Cancer Section, National Institute on Aging Geriatrics Program

**For more information, contact UMDNJ-  
School of Public Health (732) 235-9450 or go  
to**

**[www.cancerandaging.org](http://www.cancerandaging.org)**



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